

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside MM Support Group

October 5, 2025

Guest Speaker Presentation :

October's guest speaker was Shirley Thomas, representative from [Georgia SHIP](#).

Medicare Open Enrollment for 2026 is from October 15 to December 7. Ms. Thomas began the presentation with a brief overview of the Georgia State Health Insurance Assistance Program (SHIP). Its purpose is to provide information and assistance on Medicare changes and annual benefits for 2026. SHIP is an unbiased assistance program that is available in every state. Eligible participants should receive the Medicare & You 2026 handbook in the mail or in digital format. If you have not received the handbook, contact 1-800-MEDICARE or online at [Medicare.gov](#). You may also request the handbook in digital or another language format. The SHIP-GA headquarters number is 1-866-552-4464 (option 4).

Shirley Thomas' local office phone number is 470-249-3973.

-

[Medicare Part A](#) pays for hospitalization, the first 2 weeks of rehab, and some home healthcare services. It is free with no premium if you have worked at least 10 years and contributed to Medicare. If not, the premium can be extremely high, up to \$585 per month. The deductible for Part A is substantial as well. \$1676 copay is due upon admittance into the hospital for a benefit period of 60 days. If you are readmitted on day 61 or later, you pay the deductible again. Note: you must enroll for Medicare Part A when you turn 65 to avoid penalty regardless of whether you are working or not.

[Medicare Part B](#) is the medical portion benefit. There is a monthly premium of \$185 per month for 2025. The 2026 premium is projected to rise to

\$206.50. There is also a one-time deductible of \$267 for the year and it is expected to increase to \$288 for next year. Then Medicare will cover your medical cost at 80% while you will be responsible for the remaining 20% of the bill. Part B covers medical services, doctor appointments, home health care, limited hospice, and vaccines received at a clinic or pharmacy with a referral.

[Medicare Part D](#) covers prescription drugs. The premiums for Part D plans range from \$0 to \$100s per month. More importantly they do not always cover all your medications. It is vital that you thoroughly review the plans for your personal needs to be sure you have adequate coverage. On a positive note, the maximum cost for a specific medication under part D for next year is \$2100. Remember that Part D covers those prescriptions that are purchased through the pharmacy, not drugs that you receive in the hospital, doctor office, or clinic.

-

[Medicare Part C](#) is a combined A, B & D plan offered through third party insurance providers. It is also called *Medicare Advantage*. If you have an Advantage plan you need to review it in detail to determine if it is offered for 2026 and if your doctors are still in network. Drug formulary and cost tiers may also change for 2026. This year you must re-enroll in an Advantage plan whether you want the same one or something different next year. Note that 4 Cigna, 2 Humana, and 2 United Healthcare plans stopped serving Georgia in August. If you had one of those plans, the insurance provider switched your plan automatically. Be sure you always read your notices from the insurance provider. If you lose coverage for a medication due to insurance provider change you can file a [Transitional Fill Request](#) that provides an automatic extension of the drug for thirty days while you appeal the providers decision to drop coverage. SHIP can help you with this request. Advantage plan providers will send you a [NOMNC](#) notice that indicates that they will no longer have a specific procedure or medication or deny coverage. YOU have the right to appeal the decision. Part D and Advantage Plans have the most changes for the coming year. Be sure to review those parts closely to determine what changes will affect you in 2026.

The *Chronic Illness Supplemental Benefits Program* is in full effect for 2026. There will be some services not primarily health related benefits like medical transportation, pest control, meals, air quality, etc., causing chronic health illnesses. If you have two or more chronic conditions that need assistance to improve your medical condition, the plan member can request [Special Supplemental Benefits for Chronically ILL](#) (SSBCI) assistance on a case-by-case basis. Proof that you are at high-risk of hospitalization or negative health outcomes is needed to receive these benefits. Call SHIP for help with enrolling in the Medicare Savings Program and if you will qualify for the gateway application. SHIP can help you negotiate through the system. Be sure to apply online with date and time-stamp to avoid any delay or your application being lost.

Beware of phone, text, and internet fraud. Georgia is in the top ten for scams regarding social security, EBT theft, home repairs, FEMA, and veteran affairs scams. Data breaches have provided con artists with plenty of information on you already. Your calls are being recorded to get your voiceover name approval (if you say yes, ok, confirmation) to use for applications, purchases, and identity theft. Who knows how AI will aid the crooks.

Submitted by Sandy W.

Meeting Minutes
Southside MM Support Group
October 25, 2025

-

Next Meetings

Southside will meet on Saturday, November 22, 2025 @ 10:30 AM. – Hybrid Format: Virtually and in person at 3665 Cascade Road, Atlanta, GA 30331. Topic: Patient and Care Partner Voices.

For Men (*with Myeloma*) Only. Tuesday, November 25 @ 6:00 PM. Virtual.

Open Discussion and Updates

Southside welcomed two new members to the meeting. Diane was recently diagnosed due to excruciating back pain that brought her from Urgent care to the ER on October 1. The initial CT scan did not indicate anything, but a second CT scan at the hospital showed fractures, compressions, and lesions. She will begin treatment on November 1 with Darzalex, Velcade, and Revlimid. She was also referred to an oncology orthopedist for her pain. Dirk, Sandy, and Gail have all lost over five inches of height through their myeloma journey.

An important question was raised: *Is a 3-drug regimen the best treatment since a four-drug regimen is now what is most recommended?*

Jean T. is attending her first meeting as a care partner for Carolyn H. Carol was diagnosed in February 2025, had a Stem Cell Transplant on September 25, and is doing well.

Jeremiah was in lots of pain (chest, leg, arm) and struggled for over a year. He works for the City of Atlanta. He has had several tests run and everything came back normal. About two weeks ago he went into the wellness center and put some passion into his explanation that what he was feeling was not normal. They evaluated him to rule out lupus and rheumatoid arthritis. Then last Wednesday, he received his myeloma diagnosis. Jeremiah is being treated at Kaiser and Emory and begins

treatment next week. First is radiation to shrink the massive tumors/lesions in the brain. We encouraged Jeremiah to see a myeloma specialist early in his treatment. Reminder to always check your insurance to get a consultation or second opinion.

Dr. Brian Durie, one of the three co-founders of the IMF, passed away suddenly this month. The commitment of the founders to myeloma patients and care partners is in part demonstrated by the more than 150 Support Groups maintained by the IMF. He was responsible for many of the innovations in the myeloma world, including the Black Swan Initiative – another commitment to finding a cure for myeloma wherever it might be. He gave weekly blogs on topical issues related to myeloma. He created relationships all around the world and helped to establish the International Myeloma Working Group (IMWG) which meets annually in Europe and the Asian Myeloma Network. There are researchers in South America as well – all sharing research and ideas...all searching for a cure. One of the Black Swan Initiatives was the longitudinal study in Iceland, where the government supported myeloma research on all adults in the country over the age of forty. More than 80% of the adults in Iceland participated. There have been many papers presented at international conferences about myeloma at all its stages – MGUS, smoldering (SMM), and active myeloma (MM). Dr. Durie supported policy including first responders at 9/11 (September 11, 2001), noting that they had a higher incidence of myeloma and other cancers than the general population. He encouraged us all to reduce pesticides in our lives and eat a clean diet with fresh fruits and vegetables to reduce our myeloma (and other cancer) risk factors.

THANK YOU to all who were able to make a donation to the [Blood Cancer United](#) (formerly LLS) annual *Light the Night* fundraiser. Because of you, we were able to exceed our goal of \$3,000. Cynthia B. talked about her wonderful memories of attending Light the Night celebrations. She shared it was one of the most beautiful events she has ever seen. The balloons represent survivors, supporters, and those who have passed away. She encourages us all to attend Light the Night with our families in the future. Sandy B. shared that she donated but was unsure if our group was

credited. For those who still wish to donate, please do so. Subaru will match donations through next Tuesday.

Southside attended two Health Fairs on September 25 and October 4. September one (during blood cancer awareness month) was sponsored by an Atlanta neighborhood association near the Camp Creek Marketplace. Our team, led by Doris, Joyce and Nancy B., joined to educate and disseminate myeloma information for those in attendance. Morehouse School of Medicine sponsored the October event. This is an annual event, held this year at the C.T. Martin Recreation Center in SW Atlanta. There were over five hundred people and families in attendance. Yvonne J., Flora, Joyce, and Gail were able to speak to over 150 people, most of whom had never heard of myeloma, in the four hours.

Upcoming Events. Dr. Joe Mikhael (Chief Medical Officer of IMF) will present an online seminar on November 11, called *“Don’t Miss Myeloma: Making an Early and Accurate Diagnosis for an Insidious Disease”* for Georgia’s Primary Care Physicians. We ask all members of the AAMM group to share this information with their own PCP. We have witnessed, even in today’s meeting, the pain for patients and families of delayed or missed diagnoses. The online seminar is co-sponsored by the Georgia Academy of Family Physicians, the Georgia Primary Care Association, the Morehouse School of Medicine, and the IMF’s M-Power Program.

For Men (with Myeloma) Only. Anderson, Ted, Dirk, and David shared that this month there were twelve men who showed up. The meeting is for one hour. We try to make sure that everyone has an opportunity to speak. It was a very energetic exchange of information – the good and the bad.

Reflections on the Myeloma Roundtable (September 27) – held in lieu of our September meeting and sponsored by Healthtree at the Marriott Marquis. Barbara W. enjoyed seeing her own Dr. Nooka in a different setting, and being around others from this group, learning more about

myeloma. Dr. Hofmeister was a presenter along with two other Emory Winship physicians. One presentation was on nutrition research and myeloma – and a plant-based diet. Since March 2025, Flora has been with no trace of myeloma (per her bone marrow biopsy). She has been on no maintenance therapy since that time. Ted shared that Dr. Hofmeister mentioned the importance of the 4-drug regimen vs the former recommended 3-drug therapy. He also mentioned that we should make friends with acyclovir/valacyclovir to reduce our risk of shingles, and that if we are on Revlimid or Pomalyst, we should be vigilant about blood clots as a side effect. We are at 2-3 times the risk of blood clots from those drugs. Both Nooka and Hofmeister mentioned the importance of having at least a consultation with a myeloma specialist. Cautions for Clinical Trials – read the Informed Consent carefully, take your time, and try to ask lots of questions. One of the areas of concern has been the cost involved. Who will take care of any additional labs, side effects treatment, etc. Ken and others have run into finance charges that they may have to pay personally. Dr. Nooka shared that Emory Winship has in some instances failed in this area of assigning cost to Clinical Trial participants.

David shared exciting information from his reading:

- 1- JnJ announced research that showed positive results from its Phase 3 clinical trial (MajesTEC) of Darzalex and Tecvayli (a bispecific). This combination performed better than standard of care -- as early as second line.
- 2- In October, FDA approved the use of Blenrep (belantamab mafodotin-blmf) in combination with bortezomib and dexamethasone (Blvd.); and
- 3- AI is moving pharmaceutical research along at lightning speed. Research that once took 10 weeks to get results now takes 10 minutes! Stay tuned – and thank David for some positive news.

Gail shared two videos. One of Alma, who was selected as one of four people by M-Power/IMF to share her story and experiences about the

benefits of clinical trials. This can be found on YouTube. The second video was a 5-minute presentation by Dr. Joe on Highlights of Frontline, High Risk Myeloma, and What's Next with Myeloma.

Respectfully submitted,

Gail